



## RESEARCH ETHICS MONTHLY

NOVEMBER/DECEMBER 2019

Dear <<First Name>>,

As we head towards the silly season (of hurried grant applications, sabbaticals and guilty binge-watching) we wanted to send our best wishes for the holidays.

Thank you to our amazing clients, Research Ethics Monthly subscribers, <https://www.ahrecs.vip> and [Patreon](#) patrons, and our peers across Australasia and the world. We few, we happy few, we clan of human research ethics & research integrity nuts. Whether its nobler... Okay we'll stop butchering the bard and just say ***happy holidays and thank you for an amazing year.***

Please consider subscribing [at this link](#), because it is incredibly affirming and would be greatly appreciated. Subscribing is free, easy and keeps our in-house internet elf happy ("Gary stop zooming around the office in your wheelchair and stop bringing to work your digital countdown to The Mandalorian E5"). More information about the Research Ethics Monthly can be found on the [blog pages](#).





# A preliminary genealogy of research ethics review and Māori

*Lindsey Te Ata o Tu MacDonald*  
*AHRECS, Consultant*



In New Zealand, we have two separate drivers for change in research ethics for working with Māori. The first are the institutional responses to the legal requirements of government institutions to accord justice to the principles of the Treaty of Waitangi (see Te Puni Kokiri, 2001). The second arise where Māori scholars have pulled on practices and ideas within their iwi and hapū to develop a Māori centred research philosophy, that in turn has created a distinctively Māori research ethics.

I made this argument at a recent conference, in a paper to honour the late Barry Smith. Barry, in reviewing ethics applications and creating ethics policy could articulate how to negotiate both with his usual insight, grace and wit and aloha. Without him to drive developments we must think carefully about how to follow his example of synthesising the best of ethical approaches to advance Māori wellbeing and rangatiratanga (roughly translated as indigenous self-determination, see Durie, 1988).

So what is the history of research ethics approaches to research with Māori? First, the radical 1984 Labour government's privatisation agenda enshrined 'the principles of the Treaty of Wāitangi' that put in critical pieces of legislation to ensure continued Māori support. The first, and most important of these Treaty

clauses was in section 9 of the 1986 State-Owned Enterprise Act.

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## How to use the AHRECS on-call service

The AHRECS on-call service can be used for a range of tasks across the human research ethics and research integrity spheres:

- (i) Commenting on policies, resources and professional development material developed in-house;
- (ii) advising on how to respond to difficult research ethics review applications;
- (iii) advising on whether the alleged breach of the Code delete no is that is good yeah appears to relate to research misconduct

Our current on-call clients include:

1. A Group of 8 university that has engaged us for 120 hours,
2. Two small universities that have engaged us for 20 hours each, and

3. An NGO that is in going just for 10 hours.

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# The research use of online data/web 2.0 comments

Dr Gary Allen



The internet is a rich source of information for researchers. On the Web 2.0 we see extensive commentary on numerous life matters, which may be of interest to researchers in a wide range of (sub)disciplines. Research interest in these matters frequently prompts the following questions –*Can I use that in my project? Hasn't that already been published? Is research ethics review required? Is it necessary to obtain express consent for the research use?*

It's important to recognise that these questions aren't posed in isolation. Cases like the [OkCupid data scraping scandal](#), [the Ashley Madison hack](#), [Emotional Contagion](#), [Cambridge Analytica](#) and others provide a disturbing context. At a time when the use of the internet and social media is startlingly high

([Nielsen](#) 2019, [Australian Bureau of Statistics](#) 2018, commentaries such as the [WebAlive blog](#) 2019), there is also significant distrust of the platforms people are using. Consequently, there are good reasons for researchers and research ethics reviewers to be cautious about use of existing material for research, even if the terms and conditions of a site/platform specifically discuss research.

Like many ethics questions, there isn't a single simple answer that is correct all the time. The use of some kinds of data for research may not meet the National Statement's definition of human research. Use of other kinds of data may meet that definition but will be exempt from review and so not require explicit consent. Use of other kinds of data or other uses of data that involves no more than low risk can be reviewed outside an HREC meeting and others will actually have to be considered at an HREC meeting.

[Read more](#)



# Inclusion of Culturally and Linguistically Diverse populations in Clinical Trials:

Nik Zeps  
AHRECS Consultant



Clinical trials have enormous value to society as they provide the most robust means of working out whether or not particular treatments used to improve the health of our population work or not. Governments have a stated objective to increase participation in clinical trials based upon a series of assumptions that extend beyond their utility as a means to derive the highest level of reliable evidence about the efficacy and safety of interventions. One of these is that those people who are included derive a tangible benefit from doing so. Whilst this may not be true in all cases, after all up to 50% of people may receive an inferior treatment by definition, there is the potential for people to derive individual benefit, and it is often stated that those involved in a trial receive a higher standard of care than those not included. Certainly, the additional testing and closer scrutiny of people on a trial may equate in some instances to better care, but this should not be seen as a major driver as it could be argued that equitable care should be available as a universal right. A less discussed benefit is the connectedness and satisfaction that people may derive from making a tangible contribution to society through participation in clinical research. Furthermore, there may be indeterminate peer group benefits even if an individual does not benefit.

In an Australian study Smith et al (1) found that CALD people whose preferred language was not-English (PLNE) had the lowest participation rates in clinical trials. Whilst CALD people whose preferred language was English (PLE) had greater levels of enrollment than the PLNE group, they were still underrepresented by population. This has been described across the world and is identified as a pressing concern (2). Understanding why this is the case is important for a number of reasons. In multiculturally diverse countries like Australia, testing interventions where a significant proportion of the population are not included could result in evidence that is not applicable to those people. This spans across biological differences which may be relevant to drug efficacy or toxicity through to interventions such as screening that may fail to be useful in those populations. Where there is evidence that participation in a clinical trial may present specific advantages there is also the issue of injustice through exclusion of a particular group or groups of persons. Certainly, from an implementation perspective, not including a diverse group of participants and analyzing for cultural and behavioral acceptability may mean that even if an intervention has merit it fails to be taken up.

[Read more](#)

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A few profiled items from the subscribers' area:

1. [Flow to determine whether research on material published to the web/social media posts require research ethics review/consent?](#) - A Human Research Ethics resource
2. [Dracula attacks: Consent for wider use of blood](#) - A Human Research Ethics discussion activity
3. [Brainstorming - A Human Research Ethics discussion activity](#) - A discussion activity about the ethical conduct of research with brain organoids.
4. [Questionable publishers - Shell ppt with speaking notes for your modification | AHRECS version with an embedded audio by Mark Israel. Material includes a further reading sheet](#) - A research integrity professional development resource
5. [Talking about data sharing in research integrity professional development and resource material: A commentary on a Nature piece and reflecting on the epochs of ways of discussing data sharing](#) - A Research Integrity and Human Research Ethics Commentary

Please join us in saying a big thank you to our new Gold Patrons:

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- Torrens University
- University of Melbourne
- University of Southern of Queensland
- The University of Sydney Ethics Office
- University of Wollongong Ethics Unit

# Things You May Have Missed...

## Our Resource Library

1. [Quintet of study retractions rocks criminology community](#) - Science
2. [Participant understanding and recall of informed consent for induced pluripotent stem cell biobanking](#) - Papers
3. [‘Science by tweet’ prompts expression of concern, irking authors](#) - Retraction Watch
4. [Wildlife Cameras Are Accidentally Capturing Humans Behaving Badly](#) – Nature
5. (Australia) [Skin cancer doctor in hot water after papers retracted](#) – The Age
6. [23andMe, moving beyond consumer DNA tests, is building a clinical trial recruitment business](#) – STAT
7. [Involve](#) (NIHR | Established 1996, latest news August 2019)
8. [‘Misunderstanding of the academic rules’ leads to retraction of arthritis paper](#) – Retraction Watch
9. [Born Digital – The Expanding Universe of Research Content](#) - Scholarly Kitchen
10. [The female problem: how male bias in medical trials ruined women’s health](#) – The Guardian
11. [Contract cheating will erode trust in science](#) - Nature
12. [“Do we have the will to do anything about it?” James Heathers reflects on the Eysenck case](#) - Retraction Watch
13. [Ethical research — the long and bumpy road from shirked to shared](#) - Nature
14. [Highlight negative results to improve science](#) - Nature
15. [Data Management Expert Guide](#) - Guidance

## Our Blog

1. [Clergy service to HRECs: the useful paradox within secular governance of research involving human participants](#)

2. [Fighting Fiction with Fiction: A novel approach to engaging the public in bioethics of medical research](#)
3. [Pondering on whether to submit your research output to a journal?](#)
4. [Empowering and enabling participation in human research: Reflections from two Queenslanders living with Multiple Sclerosis](#)
5. [Should we Reframe Research Ethics as a Professional Ethics?](#)
6. [Ethics, Security and Privacy – the Bermuda Triangle of data management?](#)
7. [The need to seek institutional approval to survey staff – was this a misunderstanding of the purpose of Guideline 2.2.13 in the National Statement on Ethical Conduct in Human Research?](#)
8. [Smarter proportional research ethics review](#)
9. [Should you be worried about paying children to take part in research?](#)
10. [Proportional processes can sometimes be the answer to a few \(apparently competing\) problems](#)



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